



For various outputs & video of webinar for Global Humanitarian Actors (GHA):

<https://www.kirkensnodhjelp.no/en/wash>

Contact: crwash@nca.no

Findings - Mapping of support for people living with incontinence in humanitarian contexts. Through the lens of WASH, GBV and ASRH

Compilation of questions, answers and discussions from the GHA and NCA webinars

Purpose of this document

This document compiles the questions raised during two webinars, on mapping of support for people living with incontinence in humanitarian contexts. The first webinar was held for global humanitarian actors (22 June 2023) and the second for NCA staff and partners (28 June 23). This document also includes a summary of responses provided during the webinars, as well as some additional comments provided after the webinars, to expand on the information provided, when more time was available.

Presenters & facilitators of the two webinars & contributors to the responses below

Åshild Skare- Senior WASH Advisor, NCA; **Bekalu Dagne Agize** – NCA WASH Area Manager, Gambella, Ethiopia; **Chris Chatterton**- Freelance Medical and Social Researcher, Science Writer/Editor, and Advocate for People Living with Continence Issues; **Eric Weerts** – Rehabilitation Specialist, Humanity and Inclusion (HI); **Ioannis Georgiadis** – Senior WASH Advisor, NCA; **Mark Buttle** – Field Support Team (FST), WASH Cluster Coordinator- Strategy, Preparedness and Transition, OXFAM/UNICEF; **Sarah House** – Independent WASH, Equity, Inclusion and Vulnerability Consultant; **Vicky Treacy-Wong** – Lead of Nursing Group, Médecins sans Frontières (MSF); **Yahona Kadhafi** – WASH Advisor, NCA, Democratic of Congo (DRC).

Questions

A – On the mapping process	2
Q1 - Did the KIIs or FGDs include the population with incontinence?.....	3
B – Protection, disabilities, people’s experiences and stigma	3
Q2 - Can incontinence be a consequence or an indicator of elder abuse?.....	3
Q3 - Challenges identified in South Sudan and people with mental health conditions	4
Q4 - Are people with incontinence considered to have a disability?	4
Q5 - How do you target people living with incontinence, considering the issue of stigma?	5
C - Health related	7
Q6 - MSF engagement in the community or household level?.....	7
Q7 - Why this issue so overlooked in the health sector?	7
Q8 - Existence of urologists/urogyneagologists, continence nurses, midwives at cluster level	8
D – IASC, Cluster coordination and donor interest	9
Q9 - Involving IASC and Cluster level involvement	9
Q10 - Has there been much donor interest in the area of incontinence?	9
E – Numbers, NFIs and other products	11
Q11 - Numbers of people living with incontinence and predicting supplies.....	11
Q12 - How do you deal with issues around sizing and after one or two distributions?	15
Q13 - High cost of products and options of reusable products?	15
Q14 - Are there challenges experienced by the users of portable toilet chair innovation?.....	16
F – Guidance, other documentation and training	16
Q15 - Documentation on inclusive tools and approaches in humanitarian context.....	16
Q16 - Involving the International Continence Society in developing training kits	18

Outputs of the NCA Incontinence Mapping Process

The outputs of the mapping process, can be found on this website (scroll to the bottom):

<https://www.kirkensnodhjelp.no/en/wash>

1. Main report
2. Summary report
3. Supporting document 1 – Longer case studies
4. Supporting document 2 – Practical resources
5. Flyer
6. Video of the Webinar for Global Humanitarian Actors on 22 June 2023

Some of the above resources have been referred to in this document, to highlight specific pages for more information on case studies and the work of specific organisations, or in specific country contexts. Please use the above link to access the documents.

Contact: crwash@nca.no

Timings of sessions on the video

Nr	Start	Content	Speakers
1	0:00	Welcome, introductions, aim of webinar, schedule	Åshild Skare – Senior WASH Advisor, NCA & Lead for mapping process
2	5:10	Introduction to incontinence in humanitarian contexts and the mapping process	Dr Sarah House - Independent WASH, Equity, Inclusion and Vulnerability Consultant Dr Chris Chatterton - Freelance Medical and Social Researcher, Science Writer/Editor, and Advocate for People Living with Continence Issues
3	21:24	Introduction to mapping findings	Sarah House
	27:55	NCA DRC – Integrating incontinence into WASH, GBV, ASRH	Yahona Kadhafi – WASH Advisor, NCA, Democratic of Congo (DRC) & Sarah House
	34:33	MSF - Integrating continence care into healthcare responses	Vicky Treacy-Wong – Lead of Nursing Group, Médecins sans Frontières (MSF)
	40:35	HI - Supporting people with serious incontinence conditions – approaches and tools	Eric Weerts – Rehabilitation Specialist, Humanity and Inclusion (HI)
	49:31	Ukraine WASH Cluster - Leadership on incontinence support for elderly or other people	Mark Buttle – Field Support Team (FST), WASH Cluster Coordinator - Strategy, Preparedness and Transition, OXFAM/UNICEF
	1:02:36	Other examples – UNHCR, IRC, IFRC, UNFPA, REGIS and support actions	Sarah House
	1:16:58	Discussion	Ioannis Georgiadis – Senior WASH Advisor, NCA
4	1:31:47	Recommendations overview	Sarah House
	1:39:21	Q&A	Ioannis Georgiadis
5	1:49:04	Next steps, contacts, thanks and closure	Sarah House, Åshild Skare, Ioannis Georgiadis
	1:55:53	End	

A – On the mapping process

Q1 - Did the KIIs or FGDs include the population with incontinence?

Responses:

- This mapping was undertaken with humanitarian actors across sectors, and did not involve people from communities. However, both of the consultants have lived experience of incontinence, so we brought this to the mapping. We also learned about various researches, which were undertaken at community level speaking with people who live with incontinence. Information on these, is included in the mapping report.

B – Protection, disabilities, people's experiences and stigma

Q2 - Can incontinence be a consequence or an indicator of elder abuse?

Can incontinence be a consequence of elder abuse? Could it be used as one of the identifiable signs of this protection risk?

Responses:

- Yes, as a Nurse when doing an assessment of an elderly person, this would be a consideration. It might be related to emotional or physical abuse and fear, or be it related to restriction to food and fluids. There could be a range of reasons. It can be the case, if the older person's continence situation has changed from the norm for that person. But there may be different factors affecting any situation. So, if the teams know the person concerned and their usual continence situation and then if this then changes, this could indicate protection issues.
- Children and teenagers are wetting the bed, because they are traumatised and when people are very scared, they can also wet themselves, or have fecal incontinence incidents, so it would make sense that it could also be a reaction to abuse. But it would probably be hard to know for sure?
- It would also be good, to not only look at this as a possible result of abuse, but also to help people be aware that if an older person has incontinence, it can also lead to abuse. So, trying to reduce the stresses for the caregiver, can also be protective.
- It's very disturbing the level of elder abuse that goes on more generally and adding incontinence on top, it can only get worse. In the early stages of the OXFAM / HelpAge research into older people living in humanitarian contexts, some learning was undertaken on people living with dementia and incontinence and on elder abuse. This desk study is available through this link – see Sections 4.3 and 4.4: OXFAM and HelpAge, Humanitarian Innovation Fund (HIF) funded research project '*Improving the lives of older people – Understanding the barriers to inclusion of older people with incontinence in humanitarian WASH programming*' – Desk study, https://drive.google.com/file/d/13HZE_1lxVgQ71hfsNZg5oBCmnuj7H_Ge/view?usp=sharing
- The references found on elder abuse, while preparing this desk study, have also been incorporated into the NCA mapping outputs - **Supporting document 2 – Practical resources (pages 28-34)**.
- Recommendations for issues related to mental health and abuse, are also included in the Main NCA mapping report. Plus, the specific findings and recommendations for various sectoral actors, have been extracted in Word documents, as a starting point for discussion. This includes for the Protection, GBV

and MHPSS actors. These can be accessed here:

<https://drive.google.com/drive/folders/1G1en9Z2pBORmOSsouJgnzd0HVlDp6TRY?usp=sharing>

- There is a need to find a way to get Protection, GBV, MHPSS specialists to come up with some simple guidance for other actors (i.e., actors who are not Protection, GBV and MHPSS specialists), about the protection, abuse and referral good practices and what to do to try and reduce the risk of abuse, when all actors work with households with people living with incontinence.

Q3 - Challenges identified in South Sudan and people with mental health conditions

Responses:

- Information was shared on a project supported by the Netherlands Red Cross, in South Sudan. It focused on cash for WASH, but also addressed the needs of people affected by incontinence in a refugee camp. Presentation was made in the Emergency Environmental Health Forum (EEHF), 2023 (<https://www.youtube.com/watch?v=kjPu0wxZNF>).
- One of the barriers, is that over a period of time, incontinence has been hidden under 'People with Special Needs' (PSN), and organisations lump them together. But they do not realise that people with severe incontinence have a much-reduced mobility, as they cannot stand for long in distribution lines, or stay in meetings/discussions.
- It was also shared that everyone in a refugee camps, has special needs of some kind, so it is difficult to focus on people with incontinence. But a proposal was made that there is a medical link and need, which could be made more use of. But at the moment, medical organisations do not consider incontinence as an emergency, although to most of the people who have it, it is a 'fate worse than death'. It was also noted that there is no data in medical facilities, because they have not been treated in these facilities.
- In South Sudan, it took a lot of time through advocacy to get people to talk about the challenges they are facing and to get feedback on NFIs.
- It was also identified in South Sudan, that people with mental health conditions, can also live with incontinence. This issue has also been highlighted through the mapping process. This group of people have been identified in the overview of different groups of people, who may live with incontinence and in the overview of the sectoral responsibilities, proposed to support different groups of people.

Q4 - Are people with incontinence considered to have a disability?

Responses:

- The International Continence Society (ICS) and in the UK and some disability charities, consider that people with incontinence do have disabilities. Incontinence is a function of varying conditions, rather than a specific disease or condition, on its own, and the types and severity of incontinence varies greatly. So how much it will affect a person's daily life, day or night, will also vary and hence the level of disability a person faces. But it is considered a condition, that fits the criteria for a disability.
- In humanitarian contexts, we usually use the Washington Group Questions (WGQs) – Short set, for establishing if someone has a disability. These questions may not capture the aspects of disability, that someone with incontinence may face. For example, a question about whether a person faces difficulty walking, will not capture if a person is able to walk, but they are unable to leave their house, due to their incontinence. So, they are still disabled by their condition, even though they can walk and this will not be picked up by the WGQs. There is also a question on self-care, which mainly focusses, on whether a person can care for themselves and whether they need someone to help care for a person. But if a

person can care for themselves, they may still have multiple additional needs, such as for additional water, soap and other NFIs and equipment. So, there are gaps in terms of how we assess incontinence as a disability and also then subsequently for needs and resources, related to disability.

- It is possible that people with incontinence, may also have other kinds of disabilities. People could also be considered as having the same vulnerability status as people with disabilities.

Q5 - How do you target people living with incontinence, considering the issue of stigma?

Responses:

- Stigma is a very difficult issue. It cuts across all genders, ethnicity and races across the world and is a universal issue that leads to embarrassment and shame. There are some differences in cultures about how you approach and discuss this issue. But it is about sensitivity, it is about asking people in a safe environment, where they can talk freely without being overheard. It's about choosing the moment. Primary care doctors in the UK say that it is often the case that when someone goes to the doctor, the question ... *'by the way doctor'*... is often the one mentioned as the patient is leaving the consultation room, even though incontinence was actually the main question they came to the doctor to talk about. It needs openness and understanding and also a fine line between being matter of fact about it, recognising they may want to share they are embarrassed to talk about it, and not being overly "oh you poor person...". The most important things are listening and positive/kind body language. Health care professionals such as nurses and other people working on the ground, are often good at dealing with these issues.
- A personal experience was shared, of how one individual lived with stress incontinence since childhood, understood to be due to a connective tissue disorder, and was very embarrassed to talk about it. She went to the doctor in her late teens and then in her mid-30s after struggling a lot in a cold climate, but both times the doctors were dismissive and she went away, the second time in tears. It took her 10 more years to deal with it properly and then she had an operation, which has improved her situation a lot. It was shared that she was most angry about the fact that the professionals, the medics, were dismissive and not interested, and not about the embarrassment of talking about it. She would have been very grateful if they had spoken to her about it, and helped her find better ways to live with it, such as helping her know how to do pelvic floor exercises.
- Most people who are really struggling and suffering with an issue, will be grateful if you start to talk to them about it. They will probably even be very grateful that you care enough to want to talk to them about it and that you make the effort to do this. It was encouraged that we must not use, stigma and embarrassment, as an excuse to not talk about incontinence. People will generally be grateful that you care enough to ask and also that they may be able to get some help.
- Two examples:
 - Some people are just so desperate, as it is so difficult to live with. An example was shared, where an assessor was in Lebanon doing an assessment of a WASH and Shelter programme a few years ago, and was just leaving an informal settlement and an older woman pushed her older husband up to her in a wheelchair, begging the assessor for incontinence pads. This took her breath away, because, of the realisation of how desperate must they must have been to openly be asking for this support, to a total stranger in front of this group of 30 or so people, who were standing around, looking at the strange person in their camp.
 - An example from OXFAM, was where a staff member visited a household: *"We came across a house which had a pathway installed to a latrine for a young man in a wheel-chair... but the latrine was tiny, and the man clearly couldn't use it alone. His father also said that he has mental disability as well, so that he doesn't actually know when he needs the toilet, and regularly soils*

himself. On the ground along the path to the latrine were piles of soiled clothes, which the family had dumped outside as they didn't have enough water to wash them, and couldn't keep them in the house for the smell". Families in such a position, and facing such difficulties, would clearly be very grateful for people to who care about their situation enough, to come and ask questions, and also to look for possible solutions.

- In relation to the question about how to identify people with incontinence - there are different routes, which might be useful for identifying people who may be struggling and need support, for example:
 - Through disability or older persons organisations or networks or groups
 - Through community-based health workers
 - Through hygiene promotion teams
 - Through doctors and nurses, who see people in a hospital or health centre setting
 - Through community leaders
 - Through other community groups and religious organisations with strong community links
 - The Protection teams for UNHCR, were the ones who identified people and provided the support
 - The use of the rapid assessments, as mentioned in another question, which the OXFAM-led study, established can produce useful responses.
 - Through making information available on the support that can be available, if someone has this condition and where to go / who to speak to, to get support
 - Through women's safe spaces
 - Through GBV services
- It might also be possible to identify some people with this condition through the registration processes when displaced people arrive at a camp, for example, if the question is asked in the right way
- It is also proposed that awareness-raising should also be done before conducting an assessment on this issue, to encourage people to be more open
- A lot of learning is needed on the useful routes to identify people with this condition, to be able to assess their needs and give support, so any experiences of success or challenges in this area, would be very valuable to document and share
- The most important issue, will be that however the person is identified, that the process and discussions are sensitive and wherever possible, discrete and in a way and place that the person themselves feels comfortable
- NCA will be creating some guidelines and tools, for its staff and partners, on how to collect data and to identify people with incontinence

Q6 - MSF engagement in the community or household level?

I'm interested in how MSF shifts some of this really very nice healthcare facility-based work into the broader community, i.e., shifting to community or household-based management of incontinence.

Responses:

- MSF is a very medical organisation, so some of the barriers and gaps discussed in the webinar, are seen internally as well. Working in the community is not as common. We are trying to improve in the area of palliative care, but at the moment, this kind of nursing care in the community is not something that MSF focusses very much on. We tend to have a very medicalised lens in the health units and then a health promotion lens in the communities and perhaps have lost that overlap of the concentric circle, which is very much the community nursing.
- MSF [like many organisations] also often prioritises numbers and how many people can be impacted, and hence what projects will be supported, rather than the individual lens. But one thing we are really working at strengthening is that discharge moment and how to get Nurses' teams more empowered and linking with other providers in the community.
- The reflection and understanding on what is nursing is, is useful – the idea of assisting people, to perform an activity that they would normally do themselves, be it getting better, maintaining their health, dying in a dignified way, if they had the strength, or knowledge to do it themselves. This idea and also the foundation of nursing, is on self-autonomy and self-management. So, if we can strengthen this part in MSF's work and connections in the community, through strengthening the discharge moment and giving people the equipment and kits, they need to maintain their well-being, this is what we should be doing.
- For the MSF case study in the Mapping Report – please see - [Supporting Document 1 – Case studies – CS-GHA-G \(pages 68-72\)](#).

Q7 - Why this issue so overlooked in the health sector?

Responses:

- We interchangeably use the terms 'Medicine' and 'Health', but there is a difference. In humanitarian contexts, the health sector and actors are often prioritising the medical, rather than health approaches.
- Doctors may not be trained on this issue at the moment, and it may not be expected that doctors know about this subject, but incontinence is a core subject in the Nurses Curriculum. So, we need to focus more on the skills of nurses and to integrate this knowledge into the health sector responses.
- When looking at guidance, looking at the author list, it is useful to see if there is a Registered Nurse, who was on the review panel and on the list and in terms of the research? Have you got an Incontinence Nurse or specialist, or a Nurse who is supporting the elderly in your team? Often the answer is no, and it is often, only prepared by medical-dominated teams.
- Doctors also expressed a demand to have technical / medical guidance for their roles also, as they are also not confident on what they should be recommending for their patients, i.e., for example, which conditions may be treatable and which are not, and what are the next steps they should be recommending in their consultations?

Q8 - Existence of urologists/urogyneagologists, continence nurses, midwives at cluster level

A follow-up to the question on whether there are continence / pelvic floor physiotherapists in the relevant clusters: and/or, are there other continence experts, such as functional urologists/urogyneagologists, continence nurses, midwives? As incontinence really is the unknown unknown across health systems, I wonder whether having such a team of experts in the cluster/s could also help on questions of prevention and rehabilitation, even cure/mitigation in some cases beyond the question of management. and also, to train humanitarian health professionals to identify and address potential continence issues among varying populations. Have these types of responses been considered?

Responses:

- There are some examples of Physios working in humanitarian contexts, such as UNHCR noted 11, in the responses they supported with incentives in Algeria. Also, disability organisations may have a Physio in their teams, but it is not known, if they are continence physios, or are strong in these areas.
- There are a range of different technical personnel across the Clusters and sectors, but coordinating them to act on this issue, getting them together, is more challenging and most have multiple other responsibilities.
- In MSF, there is no advisor with the Physio speciality and even for Nurses, MSF does not have specialities. Each kind of patient / community facing clinician, can guide a person on getting the tangible resources and linking the health and social care aspect.
- This kind of conversation about linking different specialists up, is also very doable at field level, if you can make the time in between other responsibilities. But you do need to try and agree some kind of technical standards, such as minimum levels of provision, for example.
- A number of us, have been considering that pelvic floor exercises, could easily be added into general community mobilisation and other activities such as meetings, and can be made quite fun, but at the same time teaching a tool that can help some people living with incontinence. Some useful guidance written for children, on how to do these exercises, has been produced by the Gt Ormond Street Children's Hospital in London:
 - [https://media.gosh.nhs.uk/documents/Pelvic floor muscle exercises 1 C0180 yp A4 bw FIN AL Jul16.pdf](https://media.gosh.nhs.uk/documents/Pelvic%20floor%20muscle%20exercises%201%20C0180%20yp%20A4%20bw%20FIN%20AL%20Jul16.pdf)
 - [https://media.gosh.nhs.uk/documents/Pelvic floor muscle exercises 2 C0184 yp A4 bw FIN AL Jul16.pdf](https://media.gosh.nhs.uk/documents/Pelvic%20floor%20muscle%20exercises%202%20C0184%20yp%20A4%20bw%20FIN%20AL%20Jul16.pdf)
- Yes, we agree it would be positive to have such experts working at Cluster level, but we are a long way off at the moment. We have proposed in the mapping report, that there should be someone at Cluster Coordination team level, in each cluster/sector, who should have responsibility to make sure that this issue is responded to across their particular sector. But how we get to that level of commitment, is still to be worked out.
- We have not yet worked out how to engage effectively with the Health Sector in humanitarian contexts more broadly, than the few Health sector members in the email group. As nursing advisors, we have a broad range of responsibilities, so incontinence is something we need to think about further and work on. With our Sexual and Reproductive Health (SRH) colleagues, they are also under resourced and have prioritised other issues to work on, such as: safe births; contraception; and safe abortions.

Q9 - Involving IASC and Cluster level involvement

It is imperative to consolidate efforts by proposing to the IASC the importance of including or incorporating Incontinence issues and efforts into the WASH and Protection cluster formally. This will raise more awareness about incontinence among all humanitarian agencies within the WASH/Protection clusters or sectors and ensure there are programs targeted at incontinence management in humanitarian response.

Responses:

- Yes, we agree that it will be very important that the IASC and key clusters make this a formal requirement for their actors to work on. We are thinking that at the core of this, should be representatives from Protection, WASH and Health. But also, MHPSS and GBV specialists also need to have a core role (both of which presumably are sub-sectors of Health and Protection Clusters respectively), because of the high risk of mental health challenges and abuse. And the disability and older age specialists, should also ideally have a key role also, because of the higher prevalence of this condition in these groups of people. What we need to do, is to work out how to take these next steps to get this commitment. If anyone has any ideas, please let us know.
- The IASC would not probably be the ones, to take leadership, but we should make them aware of this issue, maybe through UNICEF, or a donor. But what is needed is a working group across Clusters, particularly, Health, Protection and WASH, to get some kind of a global view. There is some info in Sphere, but this is not really translated into on the ground ways of working at the moment.

Q10 - Has there been much donor interest in the area of incontinence?

Responses:

- Yes, to some degree. There has been some increasing interest, but still there is a long way to go. Examples, of donors who have shown interest:
 - Innovation Norway, has funded the IOM to undertake the current work, on finding new solutions for incontinence products and products to help manage babies' faeces, in Ethiopia. NCA in Gambella, has been supporting the IOM-led research on these issues. But there have been some challenges to identify organisations working in the textile industry, locally and globally, with interest in this area. For the NCA, Ethiopia case study – see: [Supporting Document 1 – Case studies – CS-NCA-D \(pages 11-14\)](#).
 - ELHRA / Humanitarian Innovation Fund – the ELHRA is funded by a number of donors, including the Norwegian and British Governments, which has funded a number of pieces of research on incontinence in humanitarian contexts over the past few years. See: [Main report – pages 157-159](#).
 - The Australian Government, has funded some large-scale studies on incontinence, alongside MHM for people with disabilities in Vanuatu, led by the London School of Hygiene and Tropical Medicine, and World Vision. See: [Main report \(page 156\)](#). Plus follow-up, trialling options for practical support, through World Vision. See: [Supporting Document 1 – Case studies – CS-GHA-D \(pages 50-56\)](#).
 - A USAID representative, shared in the GHA webinar, that she became aware of the importance of the incontinence issue and how big the problem was, and also gained enough evidence to argue for funds, after seeing the work that Mark Buttle and his team did at WASH Cluster leadership

level in Ukraine, supporting older people. You can hear more about the work in Ukraine, including how the WASH Cluster Coordinator, encouraged the WASH Cluster to act, in the webinar run on the 22 June for global humanitarian actors, which is available on the NCA WASH webpage: <https://www.kirkensnodhjelp.no/en/wash> – Also see: **Supporting Document 1 – Case studies – CS-GHA-B (pages 33-42)**. Other examples, of experiences in supporting people living with incontinence in Ukraine, can be seen in: **CS-GHA-C (pages 43-49)**; and **CS-NCA-G (pages 22-23)**.

- The Norwegian Government, has also funded this mapping process, through NCA and also agreed to a results indicator in the NCA funding agreement.
- UNICEF and WHO have also allocated funds, from their donors to working on supply of NFIs and guidance / training related to absorbent products. See: **Main report (pages 83-85)**.
- But mostly, the issue is still overlooked by donors in the humanitarian context and particularly in IDP and refugee contexts. WASH, GBV and protection teams have also come across people with disabilities in the camps with these issues, and also related to child marriage, which has resulted in fistulas. These groups of people are still not supported. So, this needs to be integrated into each sectors' work.
- There have been difficulties in getting interest in WASH for people with disabilities, although efforts have been made for around 20 years to get attention on this issue. This was since the WEDC research into WASH for people with disabilities, was undertaken, to meet people with disabilities and learn from them on the solutions they had found (research was undertaken in 2003 and the publication came out in 2005). Jones, H.E. and Reed, R.A (2005) *Water and sanitation for disabled people and other vulnerable groups: Designing services to improve accessibility*, WEDC: Loughborough University, <https://wedc-knowledge.lboro.ac.uk/details.html?id=16357> . It has been a big struggle to get agencies to take this issue seriously and to be prepared to act. But today there are also opportunities, from some increased interest in this area. So, this can offer opportunities to bring more attention also to the incontinence issue. There are examples of this already:
 - The work that the UNICEF Supply Division is doing, on standby kits for people with incontinence in humanitarian contexts. This is being undertaken with a focus on people with disabilities. But the team recognise that this work and these kits will also be useful for other people as well. So, it is opening a door to wider support.
 - A large-scale study undertaken by the London School of Hygiene and Tropical Medicine (LSHTM), which asked practitioners in the WASH sector, what are the priority areas for research – which was presented at the EEHF this year, identified that 4 out of 5 of the top priorities, were related to WASH for women, or people with disabilities and inclusion. This is a significant positive change, from previous WASH sector research priorities.
- So, there is some increasing interest from donors. If the momentum continues, it is expected within the next 5 years or so, that there will be more donors interested and active. So, all actors, are encouraged to, share the mapping outputs and the link to the webinar, with any donors which fund their projects, to increase donor awareness on these issues.
- There are also opportunities to link into the cross-sectoral nature of this condition, with links to GBV, protection, health, WASH etc – as it is an added vulnerability. So, this can also offer opportunities to attract interest from different donors, working across sectors, through highlighting how important this issue is.

Q11 - Numbers of people living with incontinence and predicting supplies

My question is more predictive in sourcing materials. My organization (I-DIEM) does emergency response work in underserved communities in the USA after disasters (often hurricanes and tornadoes). Wondering what you've found with regard to prevalence of need of products within communities per capita, so that I can advise our equity response teams on quantities of materials we may need to bring in?

Responses:

- There are many challenges in getting data on incontinence, as it is a subject which is very stigmatised and very hidden and it depends on the group of people. It has some similarities to GBV. You know it happens, and have to make some assumptions, but this does not mean it is all reported and you have numbers for it. The more work we do on this, the more likely we will be able to build up a more realistic picture.
- In Ukraine, we didn't have exact figures, but it was somewhere in the region of 1 in 3 people were elderly or had some kind of chronic health condition, or disabilities issues. Between 1 in 5, or 1 in 10, of those, needed incontinence products. It was very difficult to guess, and, in addition, the simplistic nature of programming tended to focus on people who were doubly incontinent (people with both urinary and faecal incontinence), basically those thought to be more need of adult diapers. But in the USA, data is likely to be more available.
- But also obtaining accurate data is also difficult in the European context, because of:
 - The sensitivities
 - Because of the wide variety in the conditions, both type and level of severity and if people have urinary or faecal incontinence, or both (known as 'doubly incontinent')
 - People's conditions can change over time
 - How you word the question will also result in different numbers
 - Some people don't like the word incontinence and won't want to admit this, but may share that they leak urine or faeces
- In the UK, the ranges from 10 to 20 percent can be seen, because of the issue of stigma, and some of the pad companies may even say up to 40 percent of women face incontinence. Plus, it would be expected in humanitarian contexts, that this would be on the higher end, because of the shock and traumatic experiences people have faced.
- Counting pad sales are also sometimes used to estimate the number of users, but this is also understood to be an under-estimate [and presumably also poses difficulties on how to estimate the population size, which has been covered by the sales, to calculate the percentage].
- How to identify numbers of products is also challenging, as, was noted re the Ukraine response, two pads a day, was better than nothing, but it's usually not enough, and if you have an upset stomach for example, some days you may need even more. In terms of incontinence, it would be better to have more stock than needed, than less.
- Clare Rosato-Scott, who was at the time doing her PhD at Leeds University, did some analysis of data that does exist, a summary of which we included in the guidelines, which the informal email group prepared in 2018. One other issue related to this, is that more research has focussed on high income countries, and very little has been done in lower income countries and even less in humanitarian contexts. These guidelines and other documents, which may have other useful, data related links, can be

seen through: https://drive.google.com/drive/folders/1oU_MdtCBxK_xmMLq8EQEycNE-rN4idB8?usp=share_link

- There are also opportunities for us to use data collection tools, to gather data, to start putting a clearer picture together. Even small studies, when we bring the information together, will help to build up the picture, to provide approximate ranges of numbers of people likely to be affected. But it will be ranges and not exact figures.
- An example of a study, of 1,335 older people, which was already undertaken, was by HelpAge in Cox's Bazar, who asked older people questions on their situation in the Rohingya response. 17% of respondents openly admitted they were living with / had a problem with incontinence, of which 77% of this group, said they were not getting any support. 43% of older people with disabilities, who have difficulty of getting out of their living place, also reported having incontinence. Whilst it is not clear what the specific question was that was used in this study, it does provide a ball park figure, of the magnitude of how many people may be affected. Any figures collected through surveys, should also be considered under-estimates, because of the associated stigma, as not everyone will feel comfortable to disclose their condition, or the struggles they are having with it. See: **Main report (page 109)**.
- A study by LSHTM and World Vision in Vanuatu, of 800 people with disabilities and 800 people without disabilities, found that approximately 1/3 of people with disabilities and ¼ of people without disabilities, reported having incontinence. See: **Main report (page 156)**.
- The HIF-funded research led by OXFAM and HelpAge, looking at the experiences of older people in humanitarian contexts, also looked into whether simple questions could be added into rapid assessments or KAP surveys, and whether people would answer them. Whilst the final report has not yet been seen, the research team confirmed that people did answer the questions, so this is also a useful way that information can be gathered.
- Monitoring and evaluation colleagues, will also be helpful with this area.
- See **Fig 1 and 2** - for more information.

Fig 1 – Estimates of prevalence of people living with incontinence in humanitarian and other contexts (pt 1 of 2)

People who may be living with incontinence in humanitarian contexts

Older people – including older people with dementia

Children/ teenagers – wetting the bed due to traumatic experiences

Women and girls – obstetric related - due to protracted or obstructed labour (including women and girls with FGM/C type III or IV)

People with disabilities

Women, girls, men and boys - facing serious sexual assault / rape / GBV

Women going through the perimenopause and menopause process (assume ages 40-60)

People living with chronic health conditions – such as asthma, diabetes, epilepsy, or neurological, immune-system, or connective tissue disorders – or after operations, such as for prostate cancer

People with some mental health conditions or psychosocial disabilities – for example, people with learning disabilities, or people with alcohol or drug dependency

Prevalence of people living with incontinence in humanitarian contexts

Because of the challenges noted below, establishing accurate data on how many people are living with incontinence and need support, is difficult. It is usual, to only establish ranges of people to make best estimates. So there will be a need to work through estimations and trial and error in humanitarian responses.


It is also suggested that it will be positive if people responding on the ground, manage to establish approximate ranges of people affected in their contexts, through learning from their programming responses, or through small-scale research; and this information can be shared and collated, then this will improve future estimates through triangulation across contexts.

See the next page - for current estimates

Challenges in establishing numbers of people in humanitarian contexts in need of support for incontinence

- More research has focussed on higher-income countries, and very little in middle- or lower- income countries and even less in humanitarian contexts
- Sensitivities and embarrassment of living with the condition, which can lead to reluctance for some people to initially admit the challenges they are facing – so similar to GBV survivors, numbers of people affected that are known, are likely to be under-estimates, than the real situation
- Because of wide variety (type, level and severity) in conditions, and if people have urinary or faecal incontinence, or both (known as 'doubly incontinent')
- Some people with lighter, or occasional incontinence may be able to manage on their own, if they have easy access to water, soap (a larger supply) and toilets; but people with more severe incontinence, or who are immobile, are likely to need significant support
- The condition can change over time, and when a person has a stomach upset, their incontinence can become much more difficult to manage
- How you word the question, will also result in different numbers; for example, some people don't like the word 'incontinence' (or equivalent in other languages) and won't admit having this condition, but may share they 'leak urine or faeces'
- People working in humanitarian responses, may also be embarrassed and not know how to talk about the issue with the people they are supporting

Fig 2 – Estimates of prevalence of people living with incontinence in humanitarian and other contexts (pt 2 of 2)

<p>Overall figures across all groups - UK</p> <p>In the UK, figures tend to range from 10 to 20% of the general population, because of the issue of stigma. Some pad companies even say up to 40 percent of women face incontinence. Plus, it would be expected in humanitarian contexts, this would be on the higher end, because of shock and traumatic experiences. (Credit: Dr Chris Chatterton, Freelance Medical and Social Researcher, Science Writer/Editor, and Advocate for People Living with Continence Issues)</p>		
<p>Older people and people with chronic conditions – Eastern Ukraine</p> <p>In Ukraine, exact figures were not available. Approx. 1 in 3 people, who were elderly, or had a chronic health condition, or a disability, lived with incontinence. Between 1 in 5, or 1 in 10, of those, needed incontinence products. It was very difficult to guess, and, in addition, the simplistic nature of programming tended to focus on people who were doubly incontinent (people with both urinary and faecal incontinence), basically those thought to be in most need of adult diapers. (Credit: Mark Buttle, WASH Cluster Coordinator, Eastern Ukraine humanitarian response)</p>		
<p style="text-align: center;">Older people – Rohingya response, Bangladesh</p> <p>HelpAge in Cox’s Bazar, interviewed 1,335 older people in the Rohingya response. 17% openly admitted they were living with / had a problem with incontinence, of which 77% of this group, said they were not getting any support. 43% of older people with disabilities, who have difficulty getting out of their living place, also reported incontinence.</p> <p>(Credit: HelpAge, 2018 – https://drive.google.com/file/d/1ONvnk89W7BsqiM-h6VQbFI2S7tUB2QzM/view?usp=sharing; HelpAge/Alam, S (2019) https://drive.google.com/file/d/152MPOV1123d1hsA5TYqWFzK70smGBAax/view?usp=sharing)</p>	<p style="text-align: center;">People with disabilities - Vanuatu</p> <p>A study on WASH needs in Vanuatu (800 people with disabilities and 800 people without disabilities), found approx. 1/3 of people with disabilities and ¼ of people without disabilities reported experiencing incontinence. The study also interviewed 54 of the respondents and 13 key informants in depth.</p> <p>(Credit: LSTHM and World Vision – YouTube video by Wilbur, J and MacTaggart, T, https://www.youtube.com/watch?v=030UQInPyWk)</p>	
<p style="text-align: center;">Overall figures – Various groups</p> <ul style="list-style-type: none"> • Most studies report 25% and 45% of women in the study population have urinary incontinence • Studies have found that between 1% and 39% of men (increasing with age) have urinary incontinence • Studies tend to report that less than 15% of adults in the study population have faecal incontinence • The prevalence of daytime urinary incontinence in children, decreases with age (2.0-9.0% in 7-year olds, to 1.1-3.0% in 15 to 17-years), as does bedwetting (7.0-10.0% at 7-years, to 0.5-1.7% by 16-17 years) • In rural Ethiopia, estimates are 0.2% women, 15 years+, and in Bangladesh, 0.17% of married women, live with fistula. <p>(Credit – Analysis of existing publications undertaken by Rosato-Scott, C, of Leeds University. For full references and more details, see the Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs), prepared by the Global informal email group, 2019 – (p6):https://drive.google.com/drive/folders/1oU_MdtCBxK_xmMLq8EQEvcNE-rN4idB8?usp=share_link)</p>		<div style="background-color: #4a4a8a; color: white; padding: 10px; border-radius: 15px;"> <p>Examples of prevalence data currently available</p> <p>(Noting that questions and criteria for the numbers vary)</p> </div> <div style="text-align: center; margin-top: 10px;">  <p>NORWEGIAN CHURCH AID actalliance</p> </div>

Q12 - How do you deal with issues around sizing and after one or two distributions?

Responses:

- This is always an issue with in-kind distributions, and where we have received materials for pilot projects, and some being made by beneficiaries and hence is also providing a livelihood as well. It needs more thought for incontinence products and also to understand the options of recycled products.
- There are also different needs, in terms of sizes for incontinence pads.
- The study in Ethiopia, is also looking at options for sustainable and reusable designs.
- Hygiene kits and menstrual hygiene material kits also tend to be more standard. But for incontinence the sizes and needs and types are likely to be different. There are already some good examples of teams trying to respond to the sizing issues. I think it was your team and partners, HEKS-EPER, in Ukraine, who early on, established that they should not put the incontinence pads into the kits. But when people come to pick up their hygiene kits, they can go to choose, such as in the back of a lorry, the actual sizes they need. And there was also an example of OXFAM's work in the Tsunami response, quite a few years ago, where they gave out vouchers to use in a market, for women and girls, to select the size and style of underwear they wanted.
- For comments on disposable vs reusable products – also see the responses to the question which follows.

Q13 - High cost of products and options of reusable products?

The cost of the products mentioned in Ukraine, up to \$60/70 [a month], is quite high especially given that most incontinent people live in poverty. I think as humanitarian actors we need to think on how do we come up with a kit that is affordable? Using reusable products is probably one of the ways to cut the expenses, but there is still a need to think through how we make the supplies affordable to the poor.

Responses:

- Cost is a big factor, even in medium and high-income countries. Reusable products are one solution, but:
 - Washing and drying of these products can be an issue, including particularly in cold climates and also there can be embarrassment when putting them on a line to dry.
 - And reusables are more difficult to use, if incontinence is severe or double (i.e., urine and faecal incontinence together).
 - Plus, it also creates another need for more supplies of soap and water and other issues.
 - Also, the waste disposal of items... as waste disposal is often poor in humanitarian contexts.
 - Plus, the materials are also contaminated, so we need to remember in relation to disposal.
 - It can also be a topic relevant for environmentally friendly innovations.
- There is no ideal solution, and even when considering catheters (a small tube which is inserted into the bladder and is connected to a bag outside of the body), there are also challenges. Catheters often need to be used by people with spinal cord injuries, but even with these there are problems, such as an increased risk of urinary tract infections. But without them, managing incontinence can also be very challenging and for people who are immobile, can lead to other very serious issues such as bed sores, which can also be fatal. So, all options pose challenges. Also see the Humanity and Inclusion case study, on supporting people with spinal cord injuries and other people living with disabilities.in: [Supporting Document 1 – Case studies – CS-GHA-E \(pages 57-63\)](#).

- But in terms of cost, resources and sustainability, reusables need to be a more prominent solution.
- Loving Humanity, who are an NGO which produces menstrual hygiene products and both reusable and disposable incontinence products of different sizes and provides them free in humanitarian contexts, did some learning on the issue of preferences a few years ago. They found that people sometimes prefer having access to both kinds of product, sometimes preferring to use the reusables at night and then the disposables, which are considered safer to use/ may be more secure and less likely to leak/ or of a higher absorbency, in the day, when they are out of the house. **Supporting Document 1 – Case studies – CS-GHA-A (pages 30-32).**
- This area needs a lot of trial and error, and a lot of talking to the users of these products about their preferences and experiences using them. We encourage you to document, anonymously, their feedback, as it is this kind of learning, which will help develop good practices going forward.

Q14 - Are there challenges experienced by the users of portable toilet chair innovation?

Responses:

- The main challenge we noted with portable chairs, are around emptying. On the one hand, if a sewage network is dysfunctional, then having a toilet chair solves a problem temporarily. However older or disabled people may not have enough friends, visitors or carers, to easily empty the waste. And where to empty it safely?
- There can also be challenges with chairs tipping, if the chair is not stable / fixed well enough and weight has to be put on the chair in particular areas, when getting on and off.
- Keeping chairs clean if they are in shared toilets, is also a challenge.
- Also culturally, some people may not be used to sitting, and have squatted to go to the toilet all their lives, so there may be some challenges in also getting used to this change.

F – Guidance, other documentation and training

Q15 - Documentation on inclusive tools and approaches in humanitarian context

Do we have the specific documentations on what and how Inclusive tools and approaches are used in the humanitarian context for the people with incontinence?

Responses:

- There is the toolkit, which has been developed for internal use, within Humanity and Inclusion, which has been developed over a number of years and includes a staged or levelled approach and also kindly been shared: ***Supporting people with spinal cord injuries, people with fistula, and other people living with incontinence in emergency contexts – protocols and tools used by HI***, Humanity and Inclusion (HI) - Available through this link: https://drive.google.com/drive/folders/1iN06isMpgI9vc6oDeARpHu-u_gjrrGOH?usp=sharing . See the Humanity and Inclusion case study, on supporting people with spinal cord injuries and other people living with disabilities.in: **Supporting Document 1 – Case studies – CS-GHA-E (pages 57-63).**
- There is also some guidance for specific actors, such as the “Orange manual” for fistula surgery, which was prepared by UNFPA – Link: UNFPA (2021) ***Guiding principles for clinical management and program development - Obstetric Fistula & Other Forms of Female Genital Fistula***,

<https://www.unfpa.org/publications/obstetric-fistula-other-forms-female-genital-fistula> . See the case study on fistula prevention and response, by UNFPA, MSF and partners: **Supporting Document 1 – Case studies – CS-GHA-H (pages 73-80)**.

- Plus, there are some other really great resources, such as the **Continence Product Advisor website**, which is supported by Southampton University, the University College London, the International Continence Society and the International Consultation on Urological Diseases International Consultation on Urinary Diseases. This is really positive, because it has comments from the users of the products. They are mainly users from higher income contexts, but it is still very useful information. Link: <https://www.continenceproductadvisor.org/>
- In response to increasing requests for information, the informal incontinence email group, also put together some guidance in 2018, pulling together what we knew at that time, on good practices and resources available. It was just guidance collating what we knew at the time, and was not comprehensive. Link: Rosato-Scott, C. Giles-Hansen, C. House, S. Wilbur, J. Macaulay, M. Barrington, D, J. Culmer, P. Bhakta, A. N. and Burke, L (2019) **Guidance on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs)**. LMIC-Incontinence-email-group. The set of four documents – a) Guidance document, b) 4-page Summary of the guidance document, c) Case Studies; and d) References – These can be seen through the following link: https://drive.google.com/drive/folders/1oU_MdtCBxK_xmMLq8EQEycNE-rN4idB8?usp=share_link

Other examples:

- **Fact Sheet on supporting people with incontinence from the WASH perspective**, by the Red Cross and Red Crescent Movement, <https://watsanmissionassistant.org/menstrual-hygiene-management/#LR>, or direct link here: <https://watsanmissionassistant.org/?mdocs-file=19911>
- Rosato-Scott, C., Barrington, D. J., Bhakta, A., House, S. J., Mactaggart, I. and Wilbur, J. (2020) 'Incontinence: We Need to Talk About Leaks', **Frontiers of Sanitation: Innovations and Insights 16**, Brighton: IDS, DOI: 10.19088/SLH.2020.005, <https://sanitationlearninghub.org/resource/incontinence-we-need-to-talk-about-leaks/>
- World Vision and CBM Australia (2018) **Learning from experience: Guidelines for locally sourced and cost-effective strategies for hygiene at home for people with high support needs**, https://www.cbm.org.au/wp-content/uploads/2019/02/CBM_WV_hygiene-at-home.compressed.pdf (Although, with this document, please be aware that the recommendation on the design of the reusable incontinence pads, to use towelling as the inner layer against the skin, is not correct. This is because it holds liquid and also becomes rough after some washes. The inner lining must be smooth to touch and allow liquids through it to the absorbent layers inside the product, but should not remain wet).
- Also, see the **Supporting document 2 – Practical resources**. Here you can see a wider range of examples of the information and guidance available at present.

Work planned on guidance:

- This mapping process is planning to develop guidelines and a series of tools for the NCA staff and partners and associated trainings, over the next few months.
- Plus, the HIF funded incontinence-related research teams, have also worked on a number of tools and are also currently working on some training materials.

- But there is a lot more that is needed to do in this area of developing guidance and tools, including for working with different groups of people.

Q16 - Involving the International Continence Society in developing training kits

An idea proposed is that the ICS (international Continence Society) could and should be engaged to all this work. They'd have plenty to learn of all this, but also useful expertise on prevention, rehabilitation and treatment of incontinence...perhaps co-develop, jointly with the ICS, a training kit for humanitarian health workers on types of incontinence, continence care, prevention, cure and management?

Responses:

- This sounds like a positive step if anyone can get the ICS interested? It is understood that they had an international panel, but it didn't seem like they have done much in lower income contexts?
- If they could partner with WHO, and maybe the Southampton University as well with their practical info, maybe this could be a good mix, to produce guidance, particularly, health sector focussed and for medical / health specialists, including particularly Nurses and Health Assistants. But care would need to be taken that people involved in it, understand the many resource and capacity constraints in humanitarian contexts, otherwise any outputs could be well beyond what is realistic, as support provided for people affected by humanitarian crises, is still very basic.